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Day two agenda: Community-Engaged Research Conference

Human Research Protection Office, Washington University School of Medicine in St. Louis

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Community-Engaged Research Forum
Community-Engaged Research: Exploring the unique community-academic relationship
Eric P. Newman Education Center (EPNEC)
Tuesday, September 27, 2011

7:00 – 8:00 am	Registration and Breakfast	EPNEC Main Auditorium
8:00 – 8:30 am	Welcome and Acknowledgements Bradley Evanoff, MD, MPH Dr. Richard A. and Elizabeth Henby Professor of Occupational, Industrial and Environmental Science Washington University School of Medicine	EPNEC Main Auditorium
8:30 – 9:00 am	Keynote Address <i>Challenges in Community-Engaged Research and Strategies to Overcome Them</i> Rick Kittles, PhD Scientific Director and Co-founder of African Ancestry, Inc., Associate Professor of Medicine and Epidemiology and Biostatistics University of Illinois at Chicago	EPNEC Main Auditorium
9:00 – 10:30 am	Panel Discussion <i>Facilitator</i> Consuelo H. Wilkins, MD, MSCI, Associate Professor, Department of Medicine, Geriatrics and Psychiatry, Co-Director of the Center for Community-Engaged Research in the Institute of Clinical and Translational Science, Director of the Community Outreach Program in the Nutrition Obesity Research Center, Director of “ Our Community, Our Health <i>Initial impressions, experiences, and coming together as a team</i> Lori Behrens, MSW, LCSW, Executive Director (SIDS Resources) and Caroline Vemulapalli, Research Patient Coordinator (Washington University), St. Louis Community/ University Health Research Partnership Award Recipients <i>Successes and failures: how to move forward</i> Christina Yongue Hardy, Community Research Fellow/ Program Manager and Barbara Council, Community Expert Consultant, Community Based Participatory Research Charrette Process (University of North Carolina) <i>Keys to sustaining a long-term partnership</i> Loretta Jones, MA, founder and CEO of Healthy African American Families, Phase II (HAAF), Assistant Professor at Charles R. Drew University of Medicine and Science (CDU) and Aziza Lucas-Wright, MEd, Clinical Instructor, Charles Drew University of Medicine and Science	EPNEC Main Auditorium
10:30 – 10:45 am	Break	EPNEC Lobby

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10:45 – 11:45 am **Round Table Discussions** **EPNEC Great Rooms**
Facilitator: Brenda Battle, MBA
Director, Center for Diversity and Cultural Competence
Barnes-Jewish Hospital Diversity and Cultural Competence

Round Table Discussions will be led by a facilitator and are designed to allow conference attendees to share experiences with others, network, and get potential ideas for forming or continuing a community-academic partnership. Framed in the context of new, intermediate, or long-term partnerships, attendees will share experiences with issues, as they apply, related to: Consent, Study conduct, Training, Trust, Financial issues, Sustaining the partnership, Challenges faced by the community partner, and potential areas where research could be done to fill a gap or void.

11:45 am – 1:00 pm **Lunch and Poster Presentations** **EPNEC Lobby**
For those that wish to simply enjoy lunch, please use the EPNEC Main Auditorium and EPNEC Veranda.

Networking Lunch

For those that wish to engage in discussions and networking centering around specific types of community engaged research, please go to the designated EPNEC third floor rooms. Space is limited, please sign-up at the bar area.

Leaders and research area of interest

EPNEC Room 305

Sarah Gehlert, PhD – Cancer Research
Jane Garbutt, MB ChB and Mario Castro, MD, MPH – Asthma Research
Consuelo Wilkins, MD, MSCI – Geriatric Research

EPNEC Room 306

Brad Evanoff, MD – Occupational Research: “ Ensuring the health of workers”
(injury plus health promotion)
Monique Williams, MD, MSCI – Memory and Aging Research
Mitch Sommers, PhD – Psychology Research

EPNEC Room 307

Lori Behrens, MSW, LCSW and Caroline Vemullapalli – Pediatric Research
Hannah Reinhart, MS and Susan Racette, PhD - Nutrition and Physical Therapy

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1:00 – 3:00 pm **Think Tank Discussions**
2:00 – 2:15 Break

See Room Assignments below
EPNEC Lobby

Building on conversations and presentations from earlier in the day, Think Tank sessions center around one issue relevant to community engaged research to provide a forum in which participants can discuss challenges and strategies to over them. Each discussion will be lead by a facilitator. A scribe will be present to take notes. At the end of the day, time is allocated for each group to share highlights from their discussions with the rest of the conference attendees.

Think Tank Topics

1. *Consent for community engaged research*

EPNEC Main Auditorium

Facilitators: Yvonne Josten, MPH, Assistant Professor of Medical Education and Administration and Velma McBride Murray, PhD, Endowed Chair, Education and Human Development, Professor, Human and Organizational Development, Director, Center for Research on Rural Families and Communities and Co-Director, CTSA Community Engagement Research Core (Vanderbilt University)

- I. Recruitment of patients (fliers vs phone vs in-person; role of community partnerships)
- II. Consent of patients (readability and comprehension of consent materials, understanding of risks vs benefits)

2. *Study conduct issues*

EPNEC Room 303

Facilitators: Lauren Solberg, JD, MTS, Assistant Vice President of Human Subjects Protection and Research Integrity (Meharry Medical College) and Consuelo H. Wilkins, MD, MSCI, Associate Professor, Department of Medicine, Geriatrics and Psychiatry, Co-Director of the Center for Community-Engaged Research in the Institute of Clinical and Translational Science, Director of the Community Outreach Program in the Nutrition Obesity Research Center, Director of “ Our Community, Our Health (Washington University)

- I. Keeping partners engaged throughout the process
- II. Dealing with “ lack of trust” on the part of the partners
- III. Developing feeling of shared ownership
- IV. Addressing the community’ s fear of litigation

3. *Training issues*

EPNEC Great Room B

Facilitators: Jane Garbutt, MB ChB, Research Associate Professor of Medicine and Pediatrics, Co-Director of the Center for Community-Engaged Research in the Institute of Clinical and Translational Science and Director, WU PAARC and Mario Castro, MD, MPH, Professor of Medicine and Pediatrics, Adjunct Associate Professor of Community Health at St. Louis University School of Public Health (Washington University)

- I. Training the community about research, e.g. randomization, controlled groups and use of in research methodology
- II. Feelings of “ why do I need to spend the time doing the training.”
- III. Developing research sophistication while maintaining relationships with the community

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1:00 – 3:00 pm

Think Tank Discussions

See Room Assignments below

4. Study design issues

EPNEC Seminar B

Facilitators: Sarah Gehlert, PhD, E. Desmond Lee Professor of Racial and Ethnic Diversity and Director of the Center for Community-Engaged Research in the Institute of Clinical and Translational Science and Graham Colditz, MD, DrPH, Niess-Gain Professor of Surgery, Professor of Medicine; Chief, Division of Public Health Sciences, Department of Surgery; Associate Director, Prevention and Control, Alvin J. Steman Cancer Center; and the Deputy Director, Institute for Public Health, Washington University in St. Louis Member, Institute of Medicine (Washington University)

- I. Helping partners to “lead the train” and not just follow so that community needs are met and the community does not feel used
- II. Building studies so that participants that are randomized or in the control groups have equal access to all research components at some point to avoid feelings of inequality amongst the participants
- III. Data collection and analysis: helping the community partner understand and accept this is a needed part of the study design
- IV. Constructing a Memorandum of Understanding (MOU)
- V. Negotiating Authorship

5. Financial issues

EPNEC Room 301

Facilitators: Russell Poland, PhD, Vice President for Research and Professor of Psychiatry and Behavioral Sciences (Meharry Medical College) and Bradley Evanoff, MD, MPH, Dr. Richard A. and Elizabeth Henby Professor of Occupational, Industrial and Environmental Science (Washington University)

- I. Full disclosure of what funding is available and how it will be shared by both the community partner and the academic investigator
- II. Lack of funding

6. Challenges faced by the community partner

EPNEC Great Room A

Facilitators: Loretta Jones, MA, founder and CEO of Healthy African American Families, Phase II (HAAF), Assistant Professor at Charles R. Drew University of Medicine and Science (CDU) and Aziza Lucas-Wright, MEd, Clinical Instructor (Charles Drew University of Medicine and Science)

- I. Lack of time to initiate and participate in research activities
- II. Developing the research sophistication needed to participate fully

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7. Sustainability once the initial funding concludes

EPNEC Seminar A

Facilitators: Christina Yongue Hardy, Community Research Fellow/ Program Manager and Barbara Council, Community Expert Consultant, Community Based Participatory Research Charrette Process (University of North Carolina)

- I. Should be part of the planning process
- II. How to build community resources
- III. What happens once initial funding ends

8. Research gaps and ideas for potential research partnerships

EPNEC Room 308-310

Facilitators: Hannah Reinhart, MS, Community Development Coordinator (Gateway Greening) and Susan Racette, PhD, Associate Professor, Physical Therapy, Department of Medicine – Division of Geriatrics and Nutritional Science and Department of Medicine – Division of Endocrinology, Metabolism & Lipid Research (Washington University)

- I. Where does the community see the need for conduct of research
- II. Within existing programs/ services, etc.
- III. To develop new programs/ services, etc.

3:00 – 3:15 pm **Time to prepare reports from Think Tank sessions**

3:15 – 3:45 pm **Reports from Think Tank Discussions** **EPNEC Main Auditorium**

Brenda Battle, MBA
Director, Center for Diversity and Cultural Competence
Barnes-Jewish Hospital Diversity and Cultural Competence

3:45 pm **Closing and Evaluation** **EPNEC Main Auditorium**

Bradley Evanoff, MD, MPH
Dr. Richard A. and Elizabeth Henby Professor of Occupational,
Industrial and Environmental Science
Washington University School of Medicine

4:00 pm **[Deadly Medicine: Creating the Master Race](#)** **Becker Memorial Library**
Browse through an exhibit by the United States Holocaust Memorial Museum